

KIDSNET UPDATE

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KIDSNET facilitates the collection and appropriate sharing of health data with healthcare providers, parents, MCH programs, and other child service providers for the provision of timely and appropriate preventive health services and follow up.

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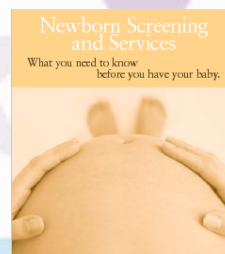
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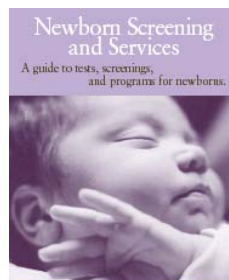
NEW!!

Educational brochures to inform parents during pregnancy, at birth, and after

Informing parents about the health care of their infants is a priority for the Department of Health. In Rhode Island, newborns are tested for nine conditions (biotinidase deficiency, congenital adrenal hyperplasia, congenital hypothyroidism, galactosemia, homocystinuria, maple syrup urine disease, medium chain acyl-coA dehydrogenase deficiency, phenylketonuria, hemoglobinopathies) and hearing loss, that can all have improved outcomes with early detection and treatment. Newborns also receive a developmental risk assessment with home visiting follow-up for at-risk infants. Infants with birth defects will be included in a birth defects registry. Starting this summer, the KIDSNET and Newborn Screening Programs are launching an ongoing educational campaign to inform parents about these tests, programs, the inclusion of their newborn in the KIDSNET system, their rights, and how to obtain more information. The educational campaign will involve three stages:



- **During pregnancy:** All ob/gyn providers are being contacted via a letter including a sample of the new brochures, which will be delivered later to their offices. These brochures inform parents about the tests that all newborns receive, and include the Family Health Information Line 1-800-942-7434 as a resource to get more information.

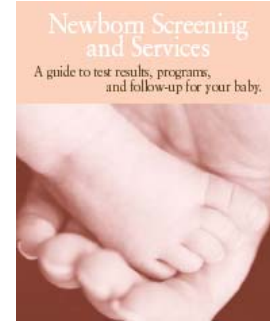


- **At birth:** Screeners performing the hearing test will coordinate the distribution of the brochures at all Rhode Island maternity hospitals and will place them in the pram, when the baby is brought to mom.

Call the KIDSNET Help Desk at 222-4220 with any questions or suggestions

- **When the baby is home:** Currently, KIDSNET sends a Hallmark congratulations card to the homes of newborns two weeks after birth. Parents will continue to receive this card, along with an insert that briefly describes the KIDSNET program and contacts.

At the third week, KIDSNET sends a letter explaining that the baby's record has been included in the database and the content and use of that information. Starting this summer, parents will be mailed the new brochure in place of the letter. Primary care physicians will be notified that these brochures will be mailed to parents. A sample brochure will be delivered to your practice.



The RI Department of Health is working with providers and hospitals to cooperate in this effort to inform parents in a timely way about the tests and programs provided to newborns and ways to help families to get more information if needed. These three brochures, available in English and Spanish, also contain information about KIDSNET, and include the KIDSNET Help Desk, 401-222-4220, as a resource for any questions related to the data in the KIDSNET system.

Additionally, please note that KIDSNET is utilized by the Newborn Screening Program, and as such, serves as a tool to assess the quality and promptness of the screening tests done during the newborn period. The quality assurance component includes efforts to ensure that all babies are screened. Since March 2004, 11 true missed blood spot screens were detected and 61 delayed specimens identified quality assurance issues.

Please keep in mind that as testing methods improve, newborns may be tested for new conditions. For the most current list of conditions that babies are tested for, visit the website at www.health.ri.gov/genetics/newborn.php, or get more information by visiting www.savebabies.org, or call the Rhode Island Department of Health's Family Health Information Line, at 1-800-942-7434, weekdays from 8:30 am to 4:30 pm.

We thank you for your cooperation in this effort, and we ask that you refer parents to any of the resources mentioned above for additional information.

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